Presumption of Incompetence: The Systematic Assignment of Guardianship Within the Transition Process

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Abstract
This article describes the potential impact that state guardianship laws may have on the transition planning process for students identified with intellectual and developmental disabilities under the Individuals with Disabilities in Education Improvement Act. The authors utilize a disability studies framework to describe how the goals of transition planning under the IDEIA—which promote autonomy and independence—appear to be in direct conflict with the goal of guardianship laws—which is to remove from young adults all or some decision making authority over their own lives. The appointment of guardians for students at the age of majority necessarily limits opportunities for students to develop decision making skills, just at the time in their lives when they should be supported by teachers and school staff to become self-determined adults. The presumption of competency as an underlying approach to all students with disabilities is discussed, and which, if used, will assist teachers, family members, and students themselves in better preparing for and successfully meeting the goals of the IDEIA. The authors suggest that parents, families and educational professionals need to be made aware of alternatives to guardianship that position the student at the center of the decision-making process in order to ensure that the goals of the IDEIA are realized for each student.

Keywords
guardianship, transition, person-centered planning, human rights

Introduction and Overview
Margaret Jean Hatch, who is known as Jenny, is a young woman who has a job, lives with friends, and is politically active in her community. But unlike some of her friends, she has been labeled with Down’s syndrome, a disability often considered synonymous with an inability to make decisions in one’s own best interest. In fact, Jenny lost her right to make decisions in 2012 when a court granted her parents a temporary guardianship order after they petitioned a local court in Virginia to become her legal guardians (Vargas, 2013). Once Jenny’s parents became her guardians, Jenny was removed from the house where she had been living and was placed in a series of group homes. She was no longer allowed to work, visit her friends, or even use her cell phone and computer. Jenny lost her right to make any and all decisions about her own life. Jenny Hatch’s guardianship case has been widely publicized. Mostly, it has been discussed as an example of the guardianship system gone awry. Here, she was living with adults whom she trusted and who provided her with support, when she was suddenly thrust into a series of group homes with strangers, and with her estranged parents as her sole decision makers. Although Jenny had graduated from high school

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several years earlier, many other young people, like Jenny, are determined (by a court) to need a guardian when they reach the age of legal majority. Once parents petition a court to become legal guardians of their young adult children, courts typically agree to appoint the parents as guardians (Payne-Christian & Stillington, 2008). As guardians, the parents are authorized to make many, if not all, decisions for their adult child. In many states, the guardianship order may last the person’s lifetime.

For parents, petitioning to become their child’s guardian can be a difficult process. To convince a court that guardianship is necessary, parents, in most states, must affirm that they believe their child is either totally or partially incompetent (Millar, 2003). Parents are presented with few, if any, alternatives to guardianship, as the teachers and school administrators, on whom they rely, are unaware of other options. In such cases, the school staff presents guardianship as the next logical step and safeguard for young people with disabilities in the transition planning process.

Most parents and families trust the professional expertise of educators to do what is best for their children. As a result, if school staff suggest to parents that they should consider petitioning the court to become their child’s guardians, that is often what they believe they are supposed to do (Millar, 2007). By deferring to the school staff, parents sometimes unknowingly privilege professionally prescribed knowledge that experts on their own children rather than themselves (Danforth, 2009; Ferguson & Ferguson, 2008; Ware, 2001). By urging parents to seek guardianship orders, school staff reconstruct the student as lacking the ability to make decisions about his or her own life. This image stands in sharp contrast to the many competencies and abilities of individual students. The idea that individuals with disabilities are unable and incompetent rather than able and competent is deeply entrenched within our society. It was not too long ago that teachers, as well as doctors, told parents of children with an intellectual disability that their children should be placed in institutions, even for the child’s lifetime (Taylor, 2008). Guardianship perpetuates this now outdated presumption of the incompetence of young people with intellectual disabilities.

We view guardianship for young adults with disabilities, which may occur within the transition planning process, as contrary to the language and purpose of the Individuals with Disabilities in Education Improvement Act (IDEIA). The IDEIA is the federal law that ensures the right of children with disabilities to a “free and appropriate public education” and to services that assist the student in transition planning beyond high school. By critiquing the appointment of parents as guardians for students as part of the transition planning process, we hope to illuminate the ways that current conceptions of disability, which are inherent in the underlying assumptions upon which guardianship is based, detract from the goals of the IDEIA. The article begins with a description of the guardianship process. A second section examines the major tenets of transition planning and critiques current practices that may encourage the appointment of guardians for students as they approach adulthood. The final section offers alternatives to guardianship that are person-centered and enable individuals greater opportunities to make decisions with or without assistance. Within this section, we highlight supported decision making as a viable option to assist individuals in making decisions, a method that finds support in the United Nations Convention on the Rights of Persons with Disabilities (CRPD). We hope that our analysis will deter educators from relying on guardianship as the presumed next step in the transition planning process for students with disabilities.

Guardianship and the Construction of Legal Capacity

Court-ordered guardianship for adults has been used in the United States and elsewhere for decades (Kanter, 2015; Salzman, 2009). However, many educators are unaware of the legal constraints that guardianship imposes on young adults with disabilities. Guardianship is the legal process by which a court appoints an individual (or organization) to substitute for the individual’s own judgment. In general, guardians may have the authority to make decisions for their “ward” about some or all aspects of their lives. The specific duties of a guardian, however, depend on the type of guardianship (Millar & Renzaglia, 2002). Guardianship is predicated on the idea that without assistance, the ward is unable to make his or her own decisions (Salzman, 2011).
Guardianship begins, in most cases, with a triggering event. For example, in the case of Jenny Hatch, her application for a Medicaid waiver triggered her parents’ decision to petition the court to become her guardians (Vargas, 2013). In the school context, the triggering event is when the student is about to reach the legal age of majority. To become a guardian, the parent submits a petition to the court, claiming that the young adult lacks decision-making capability (Millar, 2003). A notice of the petition may be sent to the potential ward (depending on the state law), and an investigation may take place, followed by a hearing in front of the judge to determine the capacity (Karp & Wood, 2006). The judge then determines if the individual meets the criteria for guardianship. The procedures for the appointment of guardians vary greatly from state to state. The evidence supporting the determination of guardianship is often highly subjective; a label of intellectual disability is insufficient in some states to support a court-ordered guardianship (Kanter, 2015; Millar, 2007). For example, Article 17A of the guardianship law in New York authorizes guardianship for people who are “mentally retarded,” “developmentally disabled,” or who have “traumatic head injuries” (N.Y. Code). This law authorizes only plenary or full guardianships, which may be based solely on the statement of two physicians. Similar practices for appointing guardians can be observed throughout the United States.

Researchers criticize the appointment of guardians based on a person’s diagnosis. An individual’s ability to care for one self cannot be determined “simply from intelligence scale scores . . . whether or not . . . a person can or cannot provide informed consent” (Lindsey, Guy, Wehmeyer, & Martin, 2001, p. 9). In short, determinations of the appropriateness of guardianship are often founded on ideological stigmas and static representations of disability.

Reform Initiatives on Guardianship

Historically, guardianship proceedings have focused on “doing good for those who cannot protect themselves” (O’Sullivan, 2001). The appointment of a guardian was and often is still seen as an important way to safeguard the individual as well as his or her property (Dinerstein, 2012; Kanter, 2015; Karp & Wood, 2006; Parry & Drugan, 2007). But over the course of time, guardianship has come under scrutiny, as reformers began to grasp the potential harm of labeling someone as incompetent “for their own good” can have on an individual (Saizman, 2009; Wright, 2010). Many policymakers and disability rights advocates began to question the effect that guardianship had on an individual’s legal right to self-determination, autonomy, and independence (Frolick, 2002; Martin, n.d.). As a result, state guardianship laws have been the subject of a variety of reform efforts. As an organization, TASH, formerly The Association for the Severely Handicapped, (2003) developed its own resolution reaffirming the damaging consequences of guardianship on the individual, stating that guardianship represents “a removal of fundamental rights and a lifelong diminution of a person’s basic control over his or her own life. Guardianship is, at its core, incompatible with real self-determination and full citizenship.”

In addition, guardianship has come under scrutiny internationally. In 2006, the United Nations adopted the CRPD. Article 12 of the CRPD specifically recommends the end of the substituted decision-making process that is part of most guardianship laws and proposes instead a system of support in which the person retains his or her legal capacity, autonomy, and dignity (Kanter, 2007, 2014). Within the CRPD, Article 12 is designed to encourage countries to develop laws and policies that provide support to people who may need help making decisions, rather than deny them their right to exercise decision making over their own lives (CRPD, 2006; Kanter, 2007). Despite these efforts, guardianship is still positioned as a common practice for individuals with particular disabilities during the transition process.

Methods Used to Embed Guardianship Within the Transition Process

The Purpose of Transition According to the IDEIA

The IDEIA, as amended in 2004, specifically mandates individualized transition planning for all qualified students with disabilities to increase the likelihood of their successful post-school employment and/or education. The outcome of such planning should be designed to take into account the individual student, his or
her interests, preferences, needs, and strengths. Accordingly, students should contribute actively to the
decision-making and planning processes (IDEIA, 2004; Kanter, 2015). To safeguard the student’s involve-
ment in the transition planning process, the IDEIA requires that students are provided an opportunity to
contribute to the decision-making and planning processes related to life after high school (Renzaglia,
Karvonen, Drasgow, & Stoxen, 2003; Zheng & Stecker, 2001). The law’s emphasis on the individual, and
his or her interests, preferences, needs, and strengths warrants transition plans to be individualized, not a
standardized, automatic process.

The goals of transition planning, which focus on autonomy and independence, appear to be in direct
conflict with the goal of guardianship, which is to facilitate the individual’s dependence on another person’s
authority to make all or some of their decisions. Nonetheless, parts of the IDEIA, together with state education
laws, may set into motion—intentionally or not—the appointment of guardians during the transition
planning process.

State Education Department’s Recommendation of Guardianship

Guardianship becomes routine in the transition process, when schools and state education departments refer
to guardianship as the next logical step within the transition planning process (Kanter, 2015; Millar, 2003).
School personnel, as well as state education departments, may also recommend guardianship as part of the
transition process. For example, New York State’s Education Department’s implementation guidelines for
transition from high school include both a comprehensive checklist and a timeline that instruct families and
caregivers to both consider and possibly seek out guardianship for students nearing the age of majority
(New York State Education Department, n.d.). Similar recommendations and suggestions have been found in
the Education Department’s transition guides and resources in states such as Arizona, Connecticut,
Florida, Georgia, Iowa, and Oregon (Arizona State Education Department, 2011; Bureau of Exceptional
Education and Student Services, Florida Department of Education, 2011; Burr, 2005; Connecticut
Interagency Transition Task Force, 2004; Connecticut Transition Task Force Parent Sub-Committee, 2005;

Uncovering the Traces of Guardianship in the IDEIA

Even though individual state educational departments and school districts determine if and when they will
suggest or recommend that a family pursue court-ordered guardianship, the IDEIA has been interpreted by
parents and school personnel to continue to receive publically funded services for their children. The first section of the IDEIA that may
prompt consideration of guardianship, relates to the notice of the transfer of rights from the parents to the
student who is about to reach the age of majority. According to Section 300.520 of the IDEIA regulations,

beginning not later than one year before the child reaches the age of majority under State law, the IEP must
include a statement that the child has been informed of the child’s rights under Part B of the Act, if any, that will
transfer to the child on reaching the age of majority.

The rights that transfer to the student at this point include the right to receive notices of and to attend indi-
vidual education program (IEP) meetings, the right to consent to reevaluations, changes in placement, and
requests for mediation or a due process hearings to resolve a dispute about evaluation, identification, eligibility,
IEP, placement, or other aspects of the entitlement to free and appropriate public education (FAPE; IDEIA,
2004; National Center on Secondary Education and Transition [NCSET], 2002). The notice of
transfer of rights is intended to encourage students to exercise independence and self-determination.

Even though the transfer of rights provision offers the young adult an exciting opportunity to assume the
role of a consenting adult, the notice of the transfer of rights is the first instance in which parents are asked
or informed about guardianship. For example, during IEP meetings in which parents were made aware of
the transfer of rights, Millar (2007) found that teachers often initiated the conversation by asking, “Do you
have a guardian?" From that point forward, parents went out of their way to file guardianship petitions. Similarly, a position statement from the Council of Exceptional Children recognizes the potential contradiction of the goals of the IDEIA’s transfer of age requirement and guardianship by observing that the notice of the transfer of rights to the student, may “lead to circumstances where parents and family members will feel compelled to obtain guardianship or other legal decision-making status over their son or daughter when they might not otherwise do so” (Lindsey et al., 2001, p. 13). The inevitability of the transfer of rights from the parents to students, and the opportunity for students to make their own decisions (in which they could possibly be taken advantage of), may coincide with the school district’s recommendation for guardianship and as the impetus for parents to seek out guardianship orders.

Another aspect of the IDEIA that may encourage parents to deny opportunities for decision making is in Section 300.520(b) of the IDEIA regulations, which provides that:

A State must establish procedures for appointing the parent of a child with a disability, or, if the parent is not available, another appropriate individual, to represent the educational interests of the child throughout the period of the child’s eligibility under Part B of the Act if, under State law, a child who has reached the age of majority, but has not been informed consent with respect to the child’s educational program, (34 C.F.R. §300.520(b))

This section of the regulations deprives the young person who is about to reach the legal age of majority of the right to consent to or refuse certain services by transferring the power to consent to another party. Further, even if parents choose not to pursue a formal guardianship, a school district may nonetheless decide on it’s own that a student is unable to provide informed consent and appoint “another appropriate individual” if the parents or guardians are unavailable (34 C.F.R. §300.520(b)). Although the appointment of “another appropriate individual” under this section of the law does not require a formal court hearing, the purpose and result of this appointment is virtually the same as a court-ordered guardianship. Thus, even without a formal guardianship, the IDEIA allows for the determination that a young adult with a disability does not have the capacity to make decisions about his or her own life, without offering the young person any opportunity to participate in decision making. Although the IDEIA does not require the appointment of a guardian, per se, the regulations do seem to create the context in which parents will move toward guardianship as a necessity to continue to ensure services for their child. Individuals with disabilities, their families, and educators need to be made aware of alternatives to outdated practices that result in the appointment of guardians.

**Reframing Disability in the Spirit of the IDEIA**

**An Essential First Step in Transition**

The purpose of the IDEIA (2004) is to promote “equality of opportunity, full participation, independent living, and economic self-sufficiency” (34 C.F.R. §300.520(c)(1)). To achieve this goal, and to support the rights of young adults with disabilities to actively participate in decisions affecting their own lives, we must begin to challenge our presumptions about disability. An essential first step is to presume competency (Biklen, 2012; Biklen & Burke, 2006; Causton-Theoharis, 2009). A presumption of competence, first described by Biklen and Burke (2006), asks educators, parents, and professionals to make the choice to start from a place that assumes individuals are competent and capable. For educators to presume competence, it is critical for them to accept their students as they are, and to assist these students in reaching their individual potential through knowing the students, their strengths, and their individual needs (see Kass-Hendrickson & Buswell, 2007). Through this process, educators and families can begin to break down attitudinal barriers that inhibit expectations and opportunities for these young adults.

As educators start to presume competency, they shift their focus toward what the student can do and what supports are necessary for the student to meet his or her goals. In the context of transition planning, the focus moves toward imagining and identifying which supports are needed to help the individual move toward and meet his or her dreams (Gallicott, 2003), Transition and service delivery that involve and center the individual move us toward this framework.
Person-Centered Planning and Supported Decision Making

Similar to the presumption of competence, person-centered planning for students “lets an individual and his or her family develop a plan based on their priorities and perceptions rather than those of the public schools or agencies” (Callicott, 2003, p. 67). Fundamental to this process is the focus on the individual and imagining the possibilities, hopes, dreams, and goals of that person and the meaningful involvement of the individual in planning his or her future (Callicott, 2003; Chambers & Childre, 2005; Meadan, Sheldon, Appel, & Degracia, 2010). Person-centered planning does not ignore disability; rather, it shifts the emphasis from a focus on the perceived limitations of the student to the capabilities of each individual student, and the resources and supports available.

Numerous methods of person-centered planning have evolved over time. For example, circle of friends (Perske, 1988), group action planning (Turnbull & Turnbull, 1996), making action plans (Forest & Lissitans, 1998), and planning alternative tomorrow’s with hope (Pearsall, O’Brien, & Forest, 1993). All of these systems of support are based on the underlying tenets of person-centered planning and utilize a team approach to “collaborate, using a problem-solving approach, to develop a holistic long-term vision and plan for the individual with a disability” (Meadan et al., 2010, p. 8). In addition to these planning methods, the CRPD has recognized the importance of support in enabling a person to exercise his or her legal capacity (Devi, 2013; Dinerstein, 2012; Kanter, 2015; Kohn, Blumenthal, & Campbell, 2013; Watson, 2013).

One approach to help people who need help in making decisions is known as “supported decision-making.” Supported decision making is a system that provides help on a voluntary basis to an individual to become empowered to make and communicate decisions about his or her life (Devi, 2013; Dinerstein, 2012; Kohn & Blumenthal, 2014; Kohn et al., 2013). Instead of assigning a substitute decision maker (i.e., a guardian) to a person who needs assistance in making decisions, supported decision making offers support to a person who needs such help, while allowing the person to retain his or her right to make decisions, and is supported to exercise this right (Flynn & Arstein-Karslake, 2014; Kohn et al., 2013). Paramount to this process is the presumption that the decision is “always in favor of the person with a disability who will be affected by the decision. The individual is the decision-maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual” (CRPD, 2007, p. 89). Supported decision making is also consistent with the presumption of competence, and recognizes that autonomy exists within interdependence. Most of us, with or without disabilities, often rely on others to help negotiate our own decisions.

Although supported decision making has been introduced in other countries, no state in the United States has yet enacted a statute based on the supported decision-making model (Kanter, 2014; Salzman, 2011). However, in most states today, many formal and informal support systems are available as alternatives to guardianship (see Table 1). All such alternatives can be utilized in combination with person-centered planning to support and meet the individual’s and family’s needs, in a manner that is more respectful of the individual’s right to dignity and autonomy than is currently provided in most guardianship laws. Families of young adults with disabilities, as well as school personnel, should consult with legal representatives or lawyer to learn about various alternatives to guardianship that may be available in their respective states.

Conclusion and Recommendations

As for Jenny Hatch, the court terminated her parents’ temporary guardianship in August 2013, and determined that Jenny could return to the home in which she had lived before the guardianship order. The couple with whom Jenny lived welcomed her back and would continue to support her in making decisions, as they had done before Jenny’s parents petitioned for guardianship. By terminating the guardianship order, the court recognized both Jenny’s right to make decisions about her own life and her need for support. Jenny’s case highlights the progression away from a system of paternalism toward a system that sustains individuals through the community-integrated supports that they choose (Vargas, 2013).

For other young people, the juxtaposition of guardianship within the transition planning process may continue to diminish opportunities for meaningfully developing and demonstrating self-determination. Families and professionals must be aware of and continue to develop alternatives to guardianship that ensure personal autonomy, so that young people with disabilities will learn and be supported to make their
Table I. Informal and Formal Alternatives to Guardianship.

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<tr>
<th>Alternative</th>
<th>Description</th>
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<tr>
<td>Advanced directive or living will</td>
<td>A legal document that can be tailored to meet specific individualized support needs. Must often, this document is utilized to support individuals in financial and medical decision making. For medical decisions, this document allows a person to appoint an agent to make some or all of the person's medical decisions (Kanter, 2015; Millar, 2013; Simons, 2011).</td>
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<tr>
<td>Durable power of attorney</td>
<td>Allows individuals to identify an agent who is legally entitled to act on the person's behalf on all or some matters. It can also include particular criteria for decisions regarding medical care or certain financial transactions (Kanter, 2015; Millar, 2013; Simons, 2011).</td>
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<tr>
<td>Special bank accounts</td>
<td>Bank accounts in which an individual is required to have a cosigner to access funds, write checks, and transact business (Kanter, 2015).</td>
</tr>
<tr>
<td>Special Needs Trust</td>
<td>Can be utilized to protect any assets or supplement funds for a person with a disability without jeopardizing access to government program funds (such as social security insurance) and without depriving the person of the right to make his or her own decisions (Simons, 2011).</td>
</tr>
<tr>
<td>Case management services</td>
<td>This type of service is usually available through community and government agencies, and works to tailor services to promote each individual's support needs. In addition, individuals and families can set up case management services that support the individual with various aspects of person-centered planning, including help in making tangible long- and short-term goals (Pitonyak, 2006).</td>
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own decisions. Through a presumption of competence, we can begin to engineer a paradigm shift, committed to recognizing the potential of all individuals to achieve independence and provide them with both access to and legitimation of their capacity to make decisions about their own lives. By focusing on the purpose and language of the IDEA, educational institutions can develop positive conceptions of disability in which individuals are included and valued within their communities, and empowered to practice decision making, with or without assistance.

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